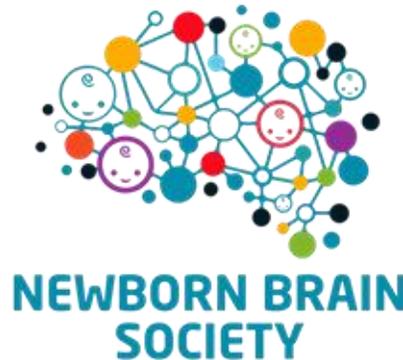


Mar 2026

# Polar Bear Care HIE Hold-A-Thon

Ready,  
Set,  
Launch!



# Agenda

1. Family education and communication
2. Trauma informed care
3. Social media strategy & April advocacy calendar
4. Final launch preparation & resources
5. Next steps & final thoughts

# Family Education & Communication

# Family Education – Why It's Critical

## Families in Crisis Need:

- ♥ Clear, compassionate information about HIE and treatment
- ♥ Understanding that holding IS possible during cooling
- ♥ Empowerment to participate actively in care
- ♥ Emotional support during trauma
- ♥ Hope for their baby's future

**Remember:** Parents in crisis may not retain information the first time

- Repetition matters
- Multiple formats help
- Written materials they can reference later
- Ongoing support throughout journey

# Core Educational Content

## About HIE & Therapeutic Hypothermia:

- What happened to my baby? (compassionate, age-appropriate explanation)
- Why does my baby need cooling therapy?
- What does the treatment involve?
- How long will it last?
- What happens after cooling ends?

## About Holding During Cooling:

- Holding during cooling IS possible and safe
- Benefits for baby's development and family bonding
- How holding works at YOUR hospital (your specific pathway)
- It's completely optional—parents are in control
- What to expect during holding (baby may be sleepy, lots of equipment)
- Safety measures in place

# Multiple Touch Points Throughout Their Journey

## Written Materials:

- HIE & therapeutic hypothermia overview handout
- Holding during cooling guide (your pathway specifics)
- FAQ sheet addressing common concerns
- Visual guides with photos (if available)
- Discharge resources and long-term support information

## Verbal Communication:

- **Physician:** Diagnosis, prognosis, medical treatment plan
- **Bedside Nurse:** Daily care, procedures, what to expect each shift
- **Before First Hold:** Step-by-step explanation, safety measures, answering questions
- **During Holding:** Check-ins, encouragement, troubleshooting
- **Social Work:** Emotional support, connecting to community resources

## Digital/Video:

- Parent testimonial videos (from toolkit)
- Links to Hope for HIE resources and support community
- Unit-specific videos (if you create them)

# Family Educational Resources

**Before implementing your pathway, staff need:**

- Understanding of HIE and therapeutic hypothermia basics
- Evidence supporting holding during TH
- Your institution's specific pathway details
- Confidence in safety protocols and troubleshooting
- Buy-in for culture change

**We want every staff member feels prepared and confident, not anxious!**

# Why Staff Education Matters

## FROM YOUR HOLD-A-THON TOOLKIT:

- Family educational handout template
- FAQ document template
- Hope for HIE resources
- Sample photos of what holding looks like
- QR codes linking to online resources

## YOU CUSTOMIZE WITH:

- Institution name and direct contacts
- Specific pathway details/criteria
- Photos of your unit
- Local community resource
- Languages spoken by your patient population



**Goal:** Have all materials printed and ready to distribute by April 1

# How to Talk to Families in Crisis

## DO

- Use simple clear language
- Check for understanding frequently
- Validate parental emotions
- Repeat key information multiple times throughout conversation
- Offer choices when possible
- Be honest about what you know and don't know
- Provide written material
- Use teach-back methodology

## DON'T

- Overwhelm with too much information at once
- Use medical terminology without a clear explanation
- Make promises you can't guarantee
- Pressure families to hold or make them feel guilty
- Assume they remember what you said yesterday
- Rush conversations – families need time to process

# Anticipate & Address Common Fears

**"Will holding hurt my baby?"** → "No. We monitor your baby continuously and guide you through everything. We only hold when it's safe, and a nurse stays with you."

**"What if their temperature goes up?"** → "We check temperature every 15-30 minutes. If it changes, we adjust warming blankets or return baby to bed if needed. We have this covered."

**"What if I drop them or pull out a tube?"** → "We secure everything carefully before you hold. Tubes have extra slack. A nurse is right beside you the entire time. You won't be able to drop your baby."

**"What if my baby doesn't respond to me?"** → "Babies on cooling and medication are often sleepy and may not open their eyes or move much. That's normal and expected. It doesn't mean they don't know you're there."

**"Am I allowed to say no?"** → "Absolutely, yes. Holding is completely optional. Some parents prefer to wait, touch instead of hold, or not hold at all—and all of those choices are okay."

# Connecting Families to Support

## Hope for HIE

- Online community
- Local chapters
- Peer mentors
- Webinars & resources
- Advocacy guidance

## Other Hospital Resources

- Social work
- Chaplain
- Mental health support
- Financial assistance
- Child life

Education provided (what and by whom)

Family understanding

Choice to hold or not (consent – center dependant)

Family preferences (special requests, cultural considerations)

± media release (photos/videos, social media, marketing, educational materials)

Documentation

# Trauma-Informed Care

# Understanding Family Trauma

## HIE DIAGNOSIS IS ACUTE TRAUMA:

- Unexpected medical crisis
- Fear of death or permanent disability
- Loss of “normal” birth experience
- Intense guilt and self-blame
- Complete loss of control
- Isolation in unfamiliar environment
- Disruption of critical bonding

## TRAUMA IMPACTS:

- How families process and retain information
- Their ability to make decisions
- Their emotional regulation (numbness, anger, being overwhelmed)
- How they interact with staff
- Their long-term mental health and PTSD risk

**Assume every HIE family is experiencing trauma**

# Principles of Trauma-Informed Care

**REALIZE**  Understand the widespread impact of trauma

Assume every HIE family is experiencing trauma

Recognize trauma affects behavior, communication, and decision-making

**RECOGNIZE**  Identify signs of trauma in families

Difficulty making decisions or processing information

Emotional overwhelm, numbness, or dissociation

Hypervigilance about baby's condition

Anger directed at staff or withdrawal

# Principles of Trauma-Informed Care

**RESPOND**  Integrate trauma knowledge into care practices

Create predictable, calm, safe environment

Offer choices and control whenever possible

Validate emotions without judgment

Provide consistent, compassionate care

**RESIST RE-TRAUMATIZATION**  Avoid practices that increase powerlessness

Don't minimize concerns or dismiss emotions

Prevent secondary trauma (additional crises, poor communication)

Support staff experiencing vicarious trauma

# Applying Trauma Principles to Family Interactions

## Create SAFETY:

- "Your baby is being monitored continuously by this equipment"
- Explain what each machine does and what alarms mean
- Prepare them for what they'll see, hear, and experience
- Consistent caregivers when possible

## Build TRUST & TRANSPARENCY:

- Be honest: "Here's what we know, and here's what we're still learning"
- Follow through on commitments—if you say you'll update them, do it
- Admit mistakes quickly and compassionately
- No surprises—prepare them for changes in condition or care

# Applying Trauma Principles to Family Interactions

## Offer CHOICE & COLLABORATION:

- "Would you like to hold today or wait until tomorrow?"
- "What would feel most comfortable for you?"
- Include parents in care rounds and decision discussions
- Ask "What questions do you have?" not "Do you have questions?"

## Facilitate EMPOWERMENT:

- "You're the most important person in your baby's life"
- "Your voice, touch, and presence matter deeply"
- Teach them care activities they can do (diaper changes, temperature taking)

# Holding as Therapeutic Trauma Intervention

## Why Holding is Powerful for Trauma Recovery:

- ♥ Restores sense of **agency and control** in a powerless situation
- ♥ Facilitates **attachment and bonding** during crisis
- ♥ Provides **tangible way to help** their baby (active, not passive)
- ♥ Creates **positive memories** within traumatic experience
- ♥ Reduces feelings of **helplessness and regret**

# How to Support Parents During Holding

- ✓ **Prepare emotionally:** "Your baby may be very sleepy and not respond much—that's the medication and cooling, not you"
- ✓ **Stay present:** Don't leave them alone—a nurse should remain nearby
- ✓ **Normalize emotions:** "It's okay to cry. This is emotional."
- ✓ **Point out positive cues:** "See how their heart rate settled when you spoke? They know you're here"
- ✓ **Offer to take photos:** Memories matter, especially if outcomes are uncertain
- ✓ **Debrief afterward:** "How did that feel for you? What was that like?"

# When Families Decline Holding

## COMMON REASONS FAMILIES SAY NO:

- Too scared or anxious
- Feeling overwhelmed & not ready emotionally
- Cultural beliefs about handling sick babies
- Previous trauma
- Need more time to process diagnosis first
- Partner doesn't feel comfortable

## RESPECT THEIR CHOICE WITHOUT JUDGMENT

- ✓ "That's completely okay. There's no pressure. You can change your mind anytime."
- ✓ Offer alternatives: "Would you like to touch their hand or talk to them instead?"
- ✓ Don't make them feel guilty or like they're harming their baby
- ✓ Check in periodically: "Would you like to try today, or still waiting?"
- ✓ Respect their timeline—some families hold on day 3, some never do, both are okay

**Document without judgment:** "Family declined holding today, prefers to wait. Will reassess tomorrow."

# Staff Self Care

Working with HIE Families is Emotionally Intense

Witnessing acute family trauma takes a toll on staff

Vicarious/secondary trauma is real—you absorb their pain

Moral distress when outcomes are poor despite best efforts

Compassion fatigue accumulates over time

Attachment to babies and families makes losses harder

## Support Your Team:

- ✓ **Normalize** emotional responses—it's okay to feel affected
- ✓ **Provide debriefing** opportunities after difficult cases
- ✓ **Encourage self-care** practices and set boundaries
- ✓ **Access to EAP** or counseling services
- ✓ **Team support** and peer processing—you're not alone
- ✓ **Celebrate positive outcomes** together to balance the hard

# Social Media Strategy

# Amplifying Impact Beyond Your Hospital

## Social Media Allows You To:

-  Raise **HIE awareness** in your community and beyond
-  Show families at **other hospitals** what's possible
-  Celebrate your **team's commitment** to family-centered care
-  **Connect** with other participating sites nationwide
-  Contribute to a **national movement** for change
-  **Inspire** future practice changes at other institutions
-  Support **Hope for HIE** advocacy efforts

**You Don't Need to Be Social Media Experts—Just Authentic!**

# Social Media Guidance & Best Practices



DO:

Use **approved hospital social media accounts** (or coordinate with marketing dept)

Obtain **proper written consent** for any photos/videos with patients or families

**Follow HIPAA**—no identifiable patient information without explicit consent

Use official hashtags: [#HIEHoldathon](#)  
[#HIEAwareness](#) [#HoldOntoHope](#)

Tag [@NewbornBrainSociety](#) and [@HopeforHIE](#) so we can amplify

Be **positive and professional** in tone

Share **educational content** that raises awareness



DON'T:

Post patient photos without explicit written media release

Share any identifying information (names, dates, details)

Post from personal accounts claiming to represent your hospital

Make medical claims or promises about outcomes

Engage in controversial topics unrelated to HIE/Hold-a-thon

Pressure families to be featured on social media

# Social Media Content Ideas

## Educational Content

- HIE/TH facts
- Benefits of FCC
- Benefits of holding

## Behind the Scenes

- Training sessions
- Teams holding swag
- NICU space

## Testimonials (with permission)

- Parent quotes/videos
- Staff reflections

## Engagement Posts

- Polls/questions
- “Ask us anything”
- Reshare NBS/HFH content

## Updates and Celebrations

- Progress updates
- Milestones & achievements
- Thank you messages to team
- Preliminary impact numbers

# April is HIE Awareness Month

## **What HIE Awareness Month Means:**

National recognition of HIE's impact on families

Time to educate public and healthcare professionals

Advocacy for increased research funding and family support

Raising awareness to improve outcomes and support

## **Our Hold-a-thon Aligns with This Larger Movement**

You're not just implementing a policy change at your hospital—you're part of a national effort to transform how we care for babies with HIE and support their families.

# Weekly Themes

**Week 1 (April 1-6): LAUNCH & EDUCATION** 🚀

**Theme:** Understanding HIE

**Focus:** What is HIE? What is therapeutic hypothermia? Why awareness matters?

**Content:** Educational posts, statistics, basic awareness, launch announcements

**Week 2 (April 7-13): FAMILY CONNECTION** 💙

**Theme:** The Power of Touch

**Focus:** Why holding matters, benefits of family-centered care

**Content:** Science of bonding, family stories, benefits for development

**Week 3 (April 14-20): HOPE & SUPPORT** 💜

**Theme:** Hold Onto Hope (campaign theme)

**Focus:** Survivor stories, long-term outcomes, community support

**Content:** Testimonials, Hope for HIE resources, resilience, community

**Week 4 (April 21-30): ADVOCACY & IMPACT** 📣

**Theme:** Changing the Future

**Focus:** Policy change, research needs, sustaining progress beyond April

**Content:** Impact stories, advocacy calls-to-action, celebration, sustainability

# Week 1: Launch & Education

-  **Launch day social media post** (coordinated nationally - April 1)
-  **Local press release** (if pursuing media coverage)
-  **Purple lighting** at hospital entrance/building (if possible to arrange)
-  **Share HIE statistics** and educational facts
-  **Post parent testimonial video**
-  **Email to staff** celebrating launch and thanking team
-  **Staff huddles** highlighting first families you'll support
-  **Distribute family education materials** to all eligible families

**Social Media Focus:** "What is HIE?" educational content, launch announcements

# Week 2: Family Connection

-  Share photos of staff preparing for holding (no patients without explicit consent)
-  Post quotes from families about their holding experience (with written permission)
-  Share research on bonding, attachment, and neurodevelopment
-  Connect families to Hope for HIE peer support
-  Highlight first successful holds (de-identified or with consent)
-  Blog post or article: "Why holding during cooling matters"
-  Infographic: Benefits of holding for babies and families

**Social Media Focus:** Benefits of family-centered care, parent quotes, the power of touch

# Week 3: Hope & Support

- ✨ Share HIE survivor stories (older children, teens, young adults thriving)
- 💜 Highlight Hope for HIE support resources and community
- 📖 Parent testimonials about their holding experience and journey
- 🎀 Purple ribbon graphics and HIE awareness images
- 😊 Staff reflections on why this work matters personally
- 💪 Posts about resilience and family strength
- 🔗 Share links to support groups, webinars, resources
- 📺 Video feature: Parent sharing their story (with consent)

Social Media Focus: "Hold Onto Hope" theme, survivor stories, support resources, community

# Week 4: Advocacy & Impact

-  Celebrate your team's incredible work and commitment
-  Share preliminary numbers: Families reached, staff educated, babies held
-  Call-to-action: Contact legislators about HIE research funding needs
-  Recognize champions and leaders who made this possible
-  Commit publicly to continuing practice beyond April
-  Thank families who participated and shared their stories
-  Post impact infographic with your site's achievements
-  Lessons learned post: What we discovered, what we'll sustain
-  Final thank you to community for supporting awareness

**Social Media Focus:** Impact, celebration, gratitude, advocacy, looking forward

# Tagging and Hashtags

- Always tag @NewbornBrains and @HopeforHIE
  - Consider tagging hospital and professional organizations when relevant
- Always use primary hashtags: #HIEholdathon, #HoldOntoHope, #PolarBearCare
  - Use additional hashtags about HIE, family-centered care, and advocacy where appropriate

# Advocacy Beyond Social Media

## Institutional Level Advocacy:

-  Present to hospital board or executive leadership
-  Request **permanent policy adoption** (if still pilot/temporary)
-  Advocate for **family-centered care standards** across all NICU populations
-  Propose **ongoing staff education** programs
-  Request **resources** to sustain and expand program

# Advocacy Beyond Social Media

## Local Level Advocacy:

-  Request **mayoral or county proclamation** declaring April "HIE Awareness Month" in your city
-  Coordinate **purple lighting** of hospital building or local landmarks
-  Invite **local media** to cover your Hold-a-thon participation
-  Host **community education event** about HIE (virtual or in-person)
-  Share **impact data** with hospital leadership and board

# Advocacy Beyond Social Media

## State/National Level Advocacy:

-  Write to state and federal legislators about HIE research funding needs
-  Share family stories with policymakers (with consent)
-  Support Hope for HIE advocacy initiatives and campaigns
-  Promote awareness through professional organizations (AAP, NANN, etc.)
-  Submit abstracts to conferences sharing your experience

# Media Engagement Opportunities

## Potential Story Angles:

Local hospital joins national family-centered care movement

Hospital policy change supports families during medical crisis

"Hold-a-thon" promotes bonding during intensive treatment

HIE Awareness Month: Local families share their stories

Innovative NICU practices at [Your Hospital]

Research and advances in neonatal brain injury treatment

## How to Engage Local Media:

Contact your hospital's **PR/marketing department first** (they may have media contacts)

Use **press release template** from toolkit

Offer **spokesperson**: Champion, medical director, or family willing to share (with consent)

Provide **B-roll or photo opportunities** (with all proper HIPAA/consent protocols)

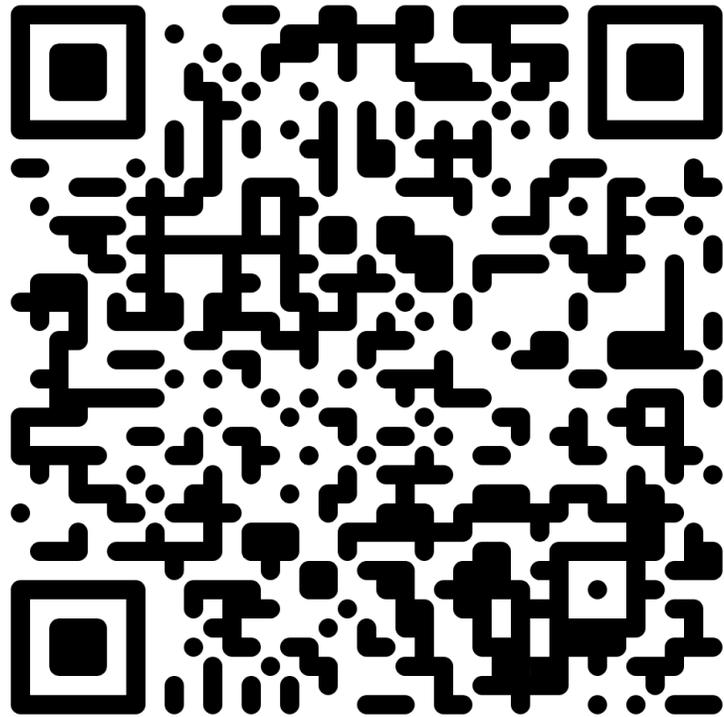
**Pitch to health reporters** at local TV stations, newspapers, radio

Emphasize **human interest angle** and local impact

# Toolkit Resources

# Website

<https://newbornbrainsociety.org/hie-hold-a-thon>



A screenshot of a web browser displaying the website for the HIE Hold-a-thon. The browser's address bar shows the URL https://newbornbrainsociety.org/hie-hold-a-thon/. The website header includes the NBS logo (Newborn Brain Society) and a navigation menu with items like ABOUT, EVENTS, MEMBERSHIP, NEWS, RESEARCH &amp; PUBLICATIONS, EDUCATION, OUR AWARDS, VOLPE'S VIEW, PROJECTS, NNCC ACCREDITATION, COMMUNITY CENTER, and SHOP MERCH. A language dropdown menu is set to English. The main content area features a teal banner with the title "HIE Hold-a-thon: Polar Bear Initiative" and the date "APRIL 2026". Below the banner, a paragraph describes the initiative: "During HIE Awareness Month, the Newborn Brain Society and Hope for HIE invite NICUs worldwide to participate in a clinician-led initiative supporting evidence-based holding and supportive touch for infants receiving therapeutic hypothermia." A circular logo for "POLAR BEAR CARE" is partially visible at the bottom left. The text "What Is the HIE Hold-A-Thon?" is followed by a description: "The HIE Hold-A-Thon is a voluntary, site-led initiative that encourages hospitals to develop their own multidisciplinary, evidence-based holding and supportive touch guidelines for infants with HIE undergoing therapeutic hypothermia." The Windows taskbar is visible at the bottom of the screenshot, showing the search bar and various application icons. The system clock in the bottom right corner indicates 9:40 PM on 1/26/2026.

# Family Info Sheet & Trifold Brochure



FAMILY INFORMATION ON POLAR BEAR CARE

## Holding Your Baby During Cooling Therapy

Your baby is receiving **therapeutic hypothermia** to help protect their brain after a difficult birth. We know this can be an overwhelming and frightening time. Science has shown that holding during hypothermia (also known as Polar Bear Care) is safe and seems to benefit both baby and parent.

### Why Holding Matters

- Supports bonding during a stressful time
- Help parents feel connected and involved in their baby's care
- It is emotionally comforting for both baby and parent

For babies and parents:

- Reduces stress
- Increases bonding
- Increases oxytocin and milk production for mothers

aren't alone and there are resources and support for you and your family.

Click below to see how a baby is preferred to be held during cooling:



Activate Windows  
Go to Settings to activate Windows.

For more information about HIE, and support for you and your family, visit:



## Holding Your Baby During Therapeutic Hypothermia

Activate Windows  
Go to Settings to activate Windows.

# Hold-a-thon Flyer

JOIN US FOR THE FIRST EVER

**Multi-Center  
Hold-A-Thon for  
Newborns Treated  
with Therapeutic  
Hypothermia**



**APRIL 1-30, 2026**  
***HIE AWARENESS MONTH***

# Social Media Toolkit

- ✓ Pre-written post templates (customize with your hospital name)
- ✓ Branded graphics and images
- ✓ Suggested posting calendar (what to post each week of April)
- ✓ Hashtag guide and tagging instructions
- ✓ Photo/video consent form templates
- ✓ Social media do's and don'ts guide

 **Pro Tip:** Connect with your hospital's marketing/communications team—they can help amplify your posts and ensure compliance with institutional social media policies.

# Advocacy Letter Templates

**To Legislators:** "Dear [Name],

As a constituent and healthcare provider caring for infants with hypoxic-ischemic encephalopathy (HIE), I'm writing during HIE Awareness Month to request your support for increased federal research funding for neonatal brain injury...

**To Hospital Leadership:** "Dear [Name],

I'm proud to report that [Hospital] participated in the national HIE Hold-a-thon during April, joining [X] hospitals across [Y] states in advancing family-centered care during therapeutic hypothermia...

**To Local Media:** "Dear [Name],

During HIE Awareness Month this April, [Hospital] is participating in a groundbreaking national initiative to support families facing one of neonatal care's most traumatic experiences..."

# Final Preparation Checklist

- ✔ **Policy & Protocols:** Pathway approved and finalized. Bedside quick-reference cards printed and accessible. Documentation process clear to all staff.
- ✔ **Staff Preparation:** All relevant staff completed training. Champions identified, visible, and ready to support. Questions and concerns addressed. Staff excited and confident.
- ✔ **Family Education:** Family education handouts printed and stocked. All staff know how to provide education to families. Hope for HIE resources available for families. Consent forms ready (if needed).
- ✔ **Communication & Advocacy:** Social media plan ready, posts drafted. Toolkit materials downloaded and reviewed. Hospital marketing team aware and involved. Media strategy determined (if pursuing). Advocacy plans in place.
- ✔ **Metrics & Tracking:** Tracking system established and tested. Person assigned to oversee data collection. Baseline data recorded. Post-Hold-a-thon survey prepared.

Next Steps & Final Thoughts

# What Success Looks Like

**Success is NOT:** ❌ Holding every single baby for maximum minutes  
❌ Perfect execution without any challenges  
❌ Competition between sites or comparison  
❌ Zero barriers or problems

**Success IS:** ✅ Families feeling supported, informed, and empowered  
✅ Safe implementation of your pathway without adverse events  
✅ Staff growing in confidence and commitment to family-centered care  
✅ Babies and families experiencing connection during crisis  
✅ Culture shift toward truly family-centered NICU practices  
✅ Lessons learned and shared with peer community  
✅ Sustained practice beyond April into standard care

**Every Single Family Who Gets to Hold Their Baby is a Success Story**

Even if it's just one family. Even if it's just for 15 minutes. That matters immensely to that family.

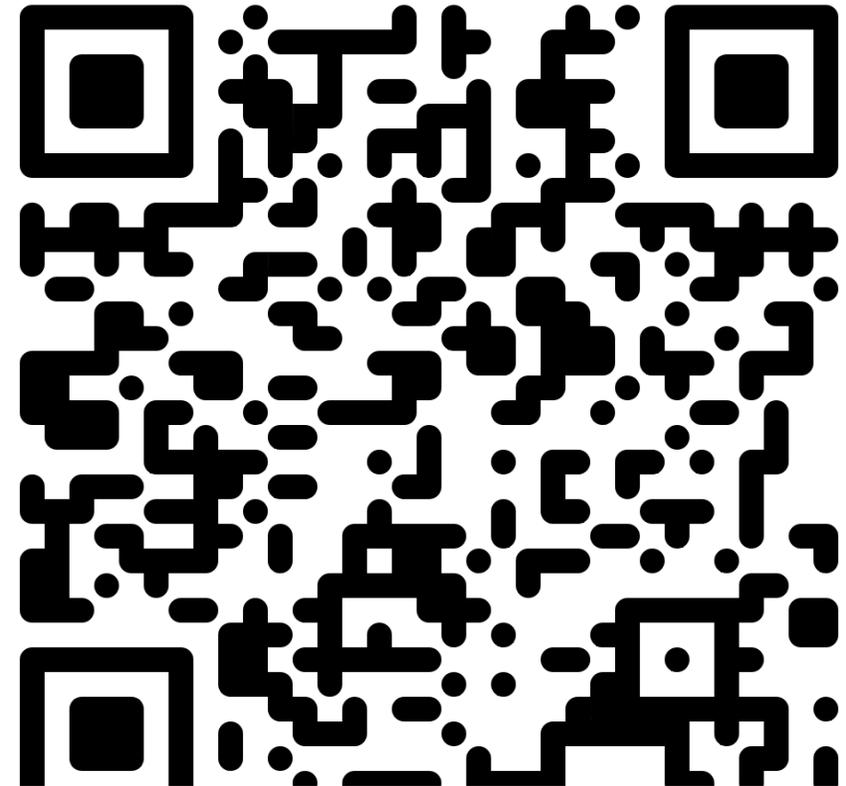
# Complete Initial Metrics Survey

**35** responses to date  
from participating centers



# Report your Institutional Readiness Score

- Submit your institutional readiness score if not already done (score will be kept anonymous)
- Received from:
  - Children's Nebraska
  - UCSF Benioff
  - UC San Diego
  - UC Davis
  - Seattle Children's
  - Lonson Health Sciences Centre
  - UW Health American Family Children's Hospital



# Before April 1:

- ✓ Finalize and print family education materials for distribution
- ✓ Review trauma-informed care principles with your team in huddles/meetings
- ✓ Set up social media posting plan - who posts, how often, content calendar
- ✓ Download social media toolkit materials and graphics
- ✓ Complete any final staff preparation - address last questions, boost confidence
- ✓ Test metrics tracking system with a practice patient/scenario
- ✓ Identify and address any last-minute barriers (equipment, space, staffing)
- ✓ Connect with hospital marketing/PR if pursuing media coverage
- ✓ Take a deep breath and get excited—you're ready for this!

Stay Tuned for April Check-Ins

# Hold Onto Hope

For the babies experiencing HIE

For the families facing unimaginable trauma

For the future of family-centered neonatal care

**You're changing lives. Thank you for your leadership & commitment!**

# Contact Information

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# Hold-A-Thon

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For Newborns with  
Hypoxic Ischemic Encephalopathy



**NBS**  
NEWBORN BRAIN  
SOCIETY

HOPE **for** HIE